

**The Nebraska Early Hearing Detection and Intervention Program
Advisory Committee Meeting
March 19, 2015
Minutes**



1:00 pm - 3:51 pm

Main Lodge, Red Oak Room, Eugene T. Mahoney State Park

Attending:

Members

Nina Baker
Kathy Beauchaine
Steve Boney
Amy Bunnell
Linsay Darnall, Jr.
Rhonda Fleischer
Cindy Johnson
Kim-Jae Kang
Richard Kang
Joan Luebbers
Stacie Ray
Colleen Richart
Pete Seiler

Guests

Cole Johnson, EDN
Teresa McEvoy, BTNRH
Dawna Lewis, BTNRH
Kelly Rausch, Parent

Interpreters

Kelly Brakenhoff
Frances Beaurivage

Staff

Jim Beavers
MeLissa Butler
Kathy Northrop

Newborn

Screening

Bloodspot Staff

Krystal Baumert
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Chair, Kathy Beauchaine, at 1:02 pm.

Open Meeting Act – Presented at the beginning of Advisory Committee Meeting by Kathy Beauchaine.

I. Welcome and Introductions

Kathy Beauchaine, Advisory Committee Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests.

II. Review of Agenda

There were no changes.

III. Review of Minutes

The meeting minutes from the December 10, 2014 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting and printed copies were available upon request. A motion to approve the minutes as published was made by Rick Kang, seconded by Nina Baker, and unanimously approved by the Committee members.

Kathy Northrop asked the Committee members if they would prefer to have printed copies of the meeting minutes included in the handout packets at each meeting. The Committee members agreed to continue distributing the meeting minutes via e-mail prior to the meeting.

IV. Presentation – Minimal/Mild and Unilateral Hearing Loss in Children

Dawna Lewis, Director of the Listening and Learning Laboratory at Boys Town National Research Hospital (BTNRH), gave a presentation on Minimal/Mild/Unilateral Hearing Loss in Children.

Nina Baker stated that several families have reported that when their children have behavioral issues it is because they are suffering from temporary hearing loss due to ear infections. The child will not hear a command, be perceived as not “obeying,” and as a result get in trouble. Or they will not hear all of the instructions and not know how to do their work in class or struggle with homework assignments. Dawna agreed, stating early childhood behavior issues often come up in her research.

Pete Seiler asked for clarification regarding the definition of unilateral hearing loss. Dawna explained unilateral hearing loss means hearing loss in one ear. One ear may not work at all or may not perform as well as the other. Pete asked if one of the issues with unilateral hearing loss is not being able to locate where sound is coming from. Dawna stated that locating sounds is one issue associated with unilateral loss. Another issue is background noise competing with the sounds a person needs to hear, such as speech. Speech recognition, even when the sound is coming straight at a person, is often a problem with a mild or unilateral hearing loss.

V. Roots and Wings Parent Weekend

Teresa McEvoy presented information about the Roots and Wings parent weekend including the following: the guiding principles, goals, topics covered during the sessions, survey results completed by families regarding the overall experience, and plans for future parent weekends.

Steve Boney asked how families received invitations each year. Teresa stated that referrals are received through various programs like the NE-EHDI Program and the Nebraska Regional Programs for Students Who Are Deaf or Hard of Hearing.

Rick Kang asked if there are plans to host a workshop which addresses issues veteran families’ face, since this workshop addresses issues families of newly identified babies. Teresa stated that Roots and Wings would love to host a birth through adult workshop and parent weekend. Rick stated that he feels a workshop addressing teenagers would be extremely beneficial, as teenage years are very tough on everyone. Teresa stated that this is something they will look into. She added many states host a family weekend where issues facing all age groups are addressed.

Pete indicated that he is concerned about the agenda including only a hard of hearing panel, as successful Deaf adults are not being represented. Pete asked if the Roots and Wings planning committee had received feedback about having more Deaf people represented. Teresa responded that in the past there had been a panel of Deaf adults and teens and feedback from parents indicated that they felt the Deaf Panel did not relate to them. Therefore, the Roots and Wings planning committee decided that the hard of hearing panel would be the most beneficial for the demographic the parent weekend targets.

The Deaf Panel was featured during the *Have You Heard What I've Heard* portion of the workshop and the planning committee has discussed bringing the Deaf Panel back during this portion of the agenda. Pete stated that he feels Roots and Wings is denying families access to the Deaf perspective by not exposing them to successful Deaf adults. Teresa responded by stating that they are looking for ways to

incorporate more of the Deaf culture into the weekend. Pete said he would be happy to attend and offer his perspective. Teresa said that in the past there were arrangements made for Deaf families to attend and often times they would withdraw at the last minute. She was not sure the reason for this, if it was intimidating for them or why they would often not follow through with representing the Deaf community during the workshop.

Linsay Darnall, Jr. mentioned that the Nebraska Association of the Deaf will be hosting a state conference on June 6, 2015 from 9:00 am – 2:00 pm and admission is free for parents. The conference will involve Deaf teenagers through the Junior Nebraska Association of the Deaf, so there is an opportunity for parents and Deaf teens to connect. Pete Seiler added the presenter will be Susan Elliott who is nationally known. Susan grew up hard of hearing and became deaf as an adult. Rhonda Fleischer stated Susan Elliot is a great speaker, adding that she was a finalist for the National Teacher of the Year award.

Rhonda also mentioned that this coming weekend, March 21-22, 2015 the collaborative parent workshops sponsored by the Nebraska Department of Education, Nebraska Hands and Voices, and the NE-EHDI Program will be held. The first one will take place in Gretna, Nebraska on Saturday March 21, 2015 and the second one will take place in Kearney, Nebraska on Sunday March 22, 2015. The presenter will be Karen Putz, who is a barefoot water skier and a deaf woman. She will be speaking, in depth, about her parenting journey.

Rhonda stated that at these workshops there are several opportunities for parents to participate. Rhonda also mentioned that Nebraska Hands and Voices hosts a coffee gathering once a month as an opportunity for parents of children who are deaf or hard of hearing get together and chat. She said that the Guide by Your Side Program hosted a parent panel last month at Boys Town National Research Hospital. And, lastly, Rhonda stated that she loves the Roots and Wings Parent Weekend because it is an awesome opportunity for Nebraska families to network and learn.

VI.EHDI Annual Meeting Highlights

Kelly Rausch is the parent of a two-year-old daughter who is hard of hearing. Kelly stated that although she enjoyed the conference, she came back with more questions than answers and realized how much she doesn't know. As a parent, she hopes to be an advocate and a source of knowledge as she learns more. Since the conference, Kelly said she has been making efforts to raise awareness through social media and posting facts on Facebook. Kelly stated one highlight for her was the State Stakeholders' Meeting, as she found both the people and the information shared at the meeting very helpful. As the parent of a fairly newly identified child, she would love to share her experience and her perspective with others. In the near future she plans to discuss her family's experience with her daughter's pediatrician, as her daughter is the first hard of hearing patient her pediatrician has had. Kelly concluded by stating that she feels her experience at the EHDI Annual Meeting will help her make her daughter a stronger, more empowered person.

Kathy Beauchaine stated that, as always, the EHDI Annual Meeting was a great opportunity for networking and to gain better awareness of what other states have available. The highlight of the meeting for her was the State Stakeholders' Meeting as it was a good opportunity to get the perspective of people from all over the state.

Rick Kang reported that during the AAP Chapter Champions Meeting, the topic of renewing the Newborn Hearing Screening Act came up, as the renewal period is approaching quickly. The importance of supporting this Act was stressed since government funding is needed in order for EHDI programs to continue.

Rick explained that the “Chapter Champion” is a person designated to work with each state EHDI program to encourage people statewide to work with EHDI, pass information along to other medical professionals, support the state program, reduce lost to follow-up, and promote doctor-to-doctor communication.

Rick also shared that he attended several sessions on Cytomegalovirus (CMV). From what he could discern, there is significant effort being invested in aggressively treating CMV, but that he does not agree that this is the wisest course. He feels the best approach is to promote education to prevent of CMV.

Rhonda Fleischer said that she attend several sessions focused on the importance of good deaf and hard of hearing role models for kids and teens. She also attended sessions which helped her learn about assessments of social skills. Her favorite session was *Man Laws for Moms: Understanding Fathers and Why We Do the Things We Do*, and she enjoyed the session so much, she has booked the presenter, Mark Keith, for some 2016 parent workshops.

MeLissa Butler added that one of her favorite sessions was also *Man Laws for Moms: Understanding Fathers and Why We Do the Things We Do*. She went on to describe some of her favorite points from the presentation including how men portray their role in the family as the “protectors” and “providers” who are not to show emotion and how women interpret men’s portrayal of their role as uncaring, when often times this isn’t really the truth.

Colleen Richart attended many sessions which focused on advocacy such as helping children learn to advocate for themselves and helping parents learn to advocate for their child. She also attended a topical session on self-identity. Coleen stated that she always enjoys the activities for parents as they are a great way to interact and meet new people.

Jim Beavers stated, that for him, the highlight of the conference was a CDC session which focused on efforts to more consistently calculate lost to follow-up percentages. He also attended a session which mentioned certain populations in the Appalachian Mountains who are unable to meet the JCIH 1-3-6 goals due to geographic challenges. So when Nebraska’s 1-3-6 statistics are compared to those of the Appalachian Mountains, Nebraska definitely looks better considering both regions have some geographic challenges to overcome.

Kathy Northrop stated overall she felt it was a very good meeting. Due to her involvement on the CMV Task Force, she attended several sessions on the topic of CMV. One session which stood out to her discussed how three hospitals in Boston were able to implement a protocol of routinely performing CMV testing without legislation in place.

Kathy N. added that there were 13 in attendance at the Nebraska State Stakeholders’ Meeting. She noted that Nebraska ranks in the top 15 among states in the number of representatives attending their State Stakeholder’s Meeting. For being a small state, this speaks very well for the support the NE-EHDI

program. Topics discussed at the State Stakeholders' Meeting included: an initiative to track the screening method used on the first outpatient screening to ensure protocol is being followed, finding a way to get Medicaid coverage in the underserved areas of Nebraska, exploring options for traveling health services in underserved areas of Nebraska, texting families with follow-up and appointment reminders, and bringing in a fresh group of parents to review *Parent Resource Guide* materials.

Kathy Beauchaine request that the reauthorization of the Newborn Hearing Screening Act should be sent out to all members of the Advisory Committee.

VII.HearU/Hearing Aid Bank Update

Stacie Ray started by thanking the NE-EHDI Program for the invaluable experience her students receive through working at the NE-EHDI Program. One of her third year graduate students is currently working on her capstone project on lost to follow-up through the NE-EHDI Program.

Julie Luedtke pointed out the NE-EHDI Program and HearU have a mutually beneficial relationship, as the graduate students working at the NE-EHDI Program are always a great asset to the team.

Stacie provided the quarterly report for HearU Nebraska and reviewed the information detailed in the handout.

Stacie also passed around a flyer for the third annual Husker for Hearing 5K Fun Run which will be held on East Campus Saturday, April 25th at 9:00 am. Pete asked if he could have an electronic copy of the flyer so he can distribute it via eblast to everyone in Lincoln and Omaha through the Nebraska Association of the Deaf.

Julie also wanted to recognize Kathy Northrop, who was elected President-elect of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA) at the Annual EHDI Meeting in Louisville, Kentucky. All members of the Committee congratulated Kathy for her achievement.

VIII.CMV Task Force Update

Rick Kang stated he is going to present information on CMV at an OB/GYN conference on May 20, 2015 in an effort to get OB/GYN doctors more involved. Rick added that from the OB/GYN perspective, CMV is not very common. Consequently, this group needs to hear the data about the impact of CMV on babies. Statistically, CMV is the number one cause of late onset hearing loss in children in the United States.

Kathy Northrop stated that the CMV Task Force is working on their next meeting date and Dr. Rick Kang has agreed to serve as chair. The Task Force is discussing the possibility of applying for a \$35,000 grant through the Stop CMV Project.

Krystal Baumert asked which states are currently performing the saliva swab on babies who do not pass their Newborn Hearing Screening. Kathy N. stated that Utah is the first and only state to pass a law mandating the test and Minnesota is exploring the idea. NCHAM is going to put together an online database so states will have somewhere to look to see what is going on with CMV activities in other states.

Pete Seiler asked Rick about best practices regarding testing for CMV, adding that it seems ideal to test a woman for CMV before she becomes pregnant. Rick responded that the ideal time to screen for CMV is the first trimester because clinical evidence shows there is an increased risk of mother-to-fetus transmission during the first trimester of pregnancy. When the woman has this information early on in the pregnancy, treatment can be started right away. Rick again stressed the importance of educating women about preventing the spread of CMV.

IX. Training Task Force Update

MeLissa Butler shared the purpose of the Hospital Training Task Force with the Advisory Committee. Many parents have expressed frustration and concern over the way the results of the Newborn Hearing Screening were communicated to them either by a nurse or a hospital screener. The purpose of the Hospital Training Task Force is to develop a training and script to help nurses and other nursery staff to know how to accurately communicate the results, understand the importance of not minimizing the results, and tell them how they can communicate with the parents in a way that doesn't alarm parent but motivates them to follow-up in a timely and appropriate manner.

MeLissa added that the Hospital Training Task Force has already met twice. Information gathered thus far has been anecdotal, so a parent survey and a professional survey will be distributed to collect actual data to help determine how the training should be developed. After the training has been conducted, the same surveys will be distributed about six months later as a way to measure the success of the training.

X. New Staff Member

Kathy Northrop announced that the NE-EHDI Program has hired a new Community Outreach Coordinator to replace Debie Seiler. Marietta Mathis is a first year Audiology student at the University of Nebraska, Lincoln and joined the NE-EHDI Program in February 2015.

XI. The NE-EHDI Program Statistics and Lost to Follow-up Information – Jim Beavers

Jim Beavers reviewed the handout entitled *January through December 2014 DOB the NE-EHDI Program Status Report*.

Julie Luedtke asked the Committee if they would be interested in seeing data presented over a period of time, perhaps three to five years so they could review trends to see how Nebraska performs on areas such as the JCIH 1-3-6 goals. Jim stated he could prepare five year trend data for the next meeting. Julie added that having this data would help the Committee identify focus areas. Kathy Northrop added the NE-EHDI Program already compiles similar data reports internally for other projects so some of the data is already available.

Kathy Beauchaine noted that at the State Stakeholders' Meeting, the group discussed the need to compare the type of screening performed in the hospital versus the type of screening performed on the outpatient screening.

Kathy B. asked Jim to describe to the Committee how the results from the hospital hearing screening machines are exported directly into the NE-EHDI data system. Jim explained the process, stating the staff from the hospital will export data onto a flash drive and upload it to a secure website called *Guardian*. Jim then exports the data into a spreadsheet, scrubs the data, and imports it into ERS which is the data system the NE-EHDI Program uses.

Kathy B. went on to explain to the Committee how important it is that the NE-EHDI Program has the capability to receive results this way, as it enables the staff to see if hospitals are over screening at the inpatient event. This process is a good quality assurance measure. Jim added this process also helps with accuracy, as it has greatly reduced the number of data entry errors.

With regards to the handout entitled *January through December 2014 DOB the NE-EHDI Program Status Report*, Rick Kang pointed out that none of the 88 babies who were discharged without a screening ended up going lost to follow-up, so those children did get screened after they were discharged from the hospital.

Rick asked about the severity of hearing loss of those 63 who were diagnosed and how many were mild, moderate, or severe to profound. Jim stated that he can have this data available next time.

Julie stated the next Status Report needs to show the percentage of babies meeting the JCIH 1-3-6 goals. Jim stated he will prepare a slide and a handout with this data for the next meeting.

In addition to the items discussed, Jim added he will present the Committee with the 2013 data he presented to the CDC and he will also send it out to the Committee ahead of time. He will also prepare more comprehensive 2014 data to present at the June meeting. Julie stated she will work with Jim on his slides for the next meeting so that they include graphics.

Rick stated he would also be interested to see how the 2.3 per thousand babies identified as deaf or hard of hearing compares to other conditions identified on Dried Blood Spot panel (DBS). Julie stated one in every 581 babies has one of the 31 conditions screened for on the DBS, with the most common being Cystic Fibrosis or Congenital Hypothyroid. The incidence for identifying a condition on the DBS is lower than identifying hearing loss through the Newborn Hearing Screening.

XII. Other

There were no other items.

XIII. Adjourn

A motion to adjourn the meeting was made by Steve Boney and seconded by Rick Kang. The meeting was adjourned at 3:51 pm.

*Next Meeting: June, 11 2015 – **1:00 pm** at Mahoney State Park, Riverview Lodge*

2015 Meeting Dates:

- September 10, 2015
- December 10, 2015

Respectfully submitted by Melissa Butler, Community Health Educator